Sociological Research online

Friendship or Facilitation: People with Learning Disabilities and Their Paid Carers

by Rebecca Pockney
University of Southampton

Sociological Research Online, Volume 11, Issue 3, <http://www.socresonline.org.uk/11/3/pockney.html>.

Received: 2 Dec 2005 Accepted: 25 May 2006 Published: 30 Sep 2006

Abstract

This article compares the composition and characteristics of the social networks of 14 people with learning disabilities with those of 24 of their paid support staff. In doing so the article not only establishes the differences in the diversity, durability and density of each group's social set, but highlights the disparity in perspective that the service users and the support staff have about their shared relationships. This is followed by a sociological discussion of why those with learning disabilities perceive their support staff as friends, while the support staff seldom consider the service users in this way, preferring to view themselves as facilitators to these individuals' friendships. The article concludes by discussing the consequences of the staff and service users' differing perspectives about their relationships, in terms of the tensions it generates in staff about their caring role and the effect it may have upon those with learning disabilities' broader social inclusion.

Keywords: Learning Disabilities, Paid Carers, Friendship

Background to study

1.1 What follows is a description of a small scale study that arose out of a much more extensive research project. The main project was principally concerned with examining the social inclusion of adults with learning disabilities. Frustrated by years of attempting to translate the government's rhetoric on inclusion into a reality for the learning disabled people with whom she worked, the researcher sought to review current social inclusion policy and practice, with a view to finding a more appropriate way of facilitating this population's inclusion.

1.2 An examination of current policies and procedures in the field revealed that most strategies aimed at reducing the social exclusion of those with learning disabilities focus on either: facilitating these individuals' community presence, by ensuring they have the opportunity to live in ordinary houses within local neighbourhoods, (DHSS, 1971, Jay Report, 1979, Kings Fund 1980) or promoting their increased community participation, by encouraging them to attend education centres, enter employment and utilise generic services and facilities (DHSS 1989). While such approaches have undoubtedly reduced the segregation from society of those with learning disabilities, sceptics argue that these initiatives have done little more than aggregate or assimilate these individuals (Cohen, 1985; Redworth and Redworth, 1997; Collins, 1997). Proponents of such a view argue that delivering social inclusion requires more than just placing people in proximity to others. It is to do with engendering a 'sense of belonging' 'including oneself and being included' and being 'cared about' rather than 'cared for' (Evans and Murcott, 1990; Gollay et al, 1978). Supporters of this perspective believe that these feelings can only be fostered through the development of valued relationships.

1.3 Unlike previous studies that had a tendency to gauge the social inclusion of those with learning disabilities in terms of the number of mainstream activities they participate in, or the quantity of social contact they have with non-service persons, the researcher became interested in examining how people with learning disabilities' relationships contribute to their feelings of social inclusion. The focus of the main

study thus became to discover: who people with learning disabilities value and what they value about their existing social contacts, what experience they have had of such valued relationships and how satisfied they are with them, what factors help or hinder their relationship development and whether they attribute any feelings of social inclusion they might have to the relationships they engage in.

1.4 The majority of the researcher's time was thus spent conducting a lengthy ethnographic study of 14 learning disabled adults. The main study took place in a local day centre facility. In order for the researcher to gain access to this service and the learning disabled people that used it, she was obliged to meet a number of the service manager's requirements. One such requirement entailed the researcher agreeing to inform the day centre staff of the study's key findings. As a consequence the researcher conducted three feedback events with a total of 42 local authority staff members. As well as providing a forum in which to disseminate information to the support staff the training events provided an opportunity to collect information from them.

1.5 Having established the nature of the learning disabled research participants' social networks and noted the esteem in which they held their support staff, the study also sought to find out how the staff's social networks were comprised and whether the service users featured in them. A comparison of the data collected from the staff with that elicited from the learning disabled research participants is what forms the basis of the secondary study reported here.

1.6 It should be stressed at this point that the breadth and depth of information gleaned from the staff in their one-off group meeting with the researcher was limited compared to the wealth of data compiled on each of the learning disabled participants during their numerous on-going encounters with the study's investigator. Indeed, given the lack of information gathered from the staff the researcher is not equipped to do much more than outline the make-up their social networks and describe the status they assign to those within them. A more extensive account explaining why the staff choose to include or omit particular people in their networks is beyond the scope of this particular study, as the researcher did not feel it appropriate to discuss the detail of the staff's wider social networks in the open forum of the training events.

1.7 It is recognised therefore that this is a partial account that does not claim to draw any definitive conclusions about why support staff and service users view one another as they do. Rather, its purpose is to investigate the purported disparity in perspective that exists between support staff and service users, propose possible reasons for this, and explore the consequences of such differing views on both parties.

1.8 The article outlines the way in which material about relationships was gathered from staff and service users and provides an account of the strategies employed to elicit information from the study's less verbally able learning disabled respondents. Information generated from a circle of intimacy exercise is then analysed and comparisons drawn about the composition of each group's social networks. The article goes on to explore how people with learning disabilities perceive their relationships with their paid carers, before examining how, in turn, the paid carers view their relationships with their clients. The ways in which staff and service users view one another are shown to differ. The possible reasons for theses discrepancies are explored and their consequences discussed.

The research population and sample

2.1 According to the Department of Health people with learning disabilities are those who have been assessed, prior to reaching adulthood, as having a reduced ability to: understand complex information, learn new skills or cope independently (DoH 2001)

2.2 For the purposes of this article people referred to as *paid carers* are individuals who receive financial remuneration for providing 'human support services' to those with learning disability. In this case they were either local authority employees who staffed one of the two regional day centres, or individuals who worked for a local specialist employment agency.

2.3 People with learning disabilities are a heterogeneous group with a wide variety of physical, sensory, cognitive and communication abilities. The lead researcher was committed to trying to represent this diversity within the research sample and thus spent three months at the local authority day centre in which the research was conducted getting to know some of the 160 service users prior to attempting to engage any of them in the study. Once familiar with each person's function and mode of communication the researcher was able to select a group of 20 individuals with a representative range of abilities. From this original set 14 participants were eventually recruited (seven men and seven women) who ranged in age from 23 to 66 years. (Five of the original 20 declined to take part in the study and one individual became too unwell to participate.) All 14 of those recruited had a learning disability. In addition to this, four had little or no verbal communication, two had limited vision, one was hearing-impaired, three were wheelchair users and one displayed what is described as 'challenging behaviour' (Emmerson 1995, Qureshi & Alborz 1992)

2.4 The staff sample was comprised of 24 individuals who attended one of the three staff training events run by the researcher. Little else is known about this group as the researcher made a conscious decision not to collect any specific demographic data about them.

The research project

3.1 Eliciting information about valued relationships from the learning disabled research sample was not straightforward. The fieldwork was conducted over a period of seven months in 2003. A range of different approaches were employed to build up a picture of these individual social networks. The researcher spent approximately 2 weeks with each research participant observing how, where, and with whom they conducted their 'friendships'. During this time the researcher also helped the participants to record a social

diary and take photographs of who they spent their time with. The researcher also drew life-maps based on the participants' narratives about their earlier lives depicting who they had had contact with in the past (Gray & Ridden 1999). The information gleaned from the ethnographic observations, participants' diaries, photographs and life-maps formed the basis of a series of ongoing 'discussions' in which participants were encouraged to talk about each of their social relationships. These discussions were conducted in a pragmatic way at times and places that suited the participants. Verbal communication between the researcher and the participants was supplemented, whenever necessary, with visual images (Rebus symbols) and sign language (Makaton) (Dertheridge & Dertheridge 2002. Birkett EM. 1984)

3.2 The researcher's time with each learning disabled participant culminated in working together to construct a 'circle of intimacy' (Smull & Burke Harrison 1992). Circles of intimacy have been widely used by researchers with a number of different research participants, including children and the elderly. They have also been referred to Personal Community Maps or Net-boards (Pahl & Spencer 2004, Wales et al 2001) Whatever the term used to describe this particular data collection tool this diagrammatic device enables people to indicate the value that they attribute to those in their lives, relative to one another. It involves individuals placing the names of significant others within a set of concentric circles centred around themselves. The closer a social contact is placed to the central person, the greater the value attributed to them.

3.3 In this case, the researcher provided each participant with a sheet of A3 paper on which was drawn four concentric circles, the central one of which contained a photograph of the individual. The participants were asked to consider each of their social contacts, from a list they had previously compiled with the researcher, and place an image of that person somewhere within one of concentric circles, according to the value they assigned to them. Having been shown what to do each participant was able to undertake the task with minimal assistance from the researcher.

The learning disabled research participants' social networks

4.1 Analysis of each research participant's circles of intimacy (in conjunction with the other data collected) revealed a good deal about the diversity, durability and density of their relationships. It showed, for instance, that the learning disabled research participants had an average of 15 social contacts, which predominantly consisted of family members, paid carers and other people with learning disabilities. It also showed that although these individual had some long-standing relationships their contacts were not on the whole very durable. Aside from family ties their relationships tended to be restricted to the present, with little accumulation of social contacts over time. In addition their lives were rather compartmentalised. This was reflected by the fact that their social networks tended to be divided into a number of smaller 'factions' or social groups who had limited contact with one another. It appeared, for instance, that the research participants' families (where they had them) had little to do with their residential carers who, in turn, had minimal contact with their day centre staff.

4.2 These findings are commensurate with earlier studies that suggest that people with learning disabilities have up to a third fewer social contacts than their non-disabled peers (Wesolowski, 1987), that these contacts are on the whole limited to family, staff and service users (Atkinson 1987, Richardson and Richie 1989) and that this is the case regardless of the individual's age, sex, level of ability or support background (Cooper 1998, Newton et al 1996, Ralph 1995).

The support staff's social networks

5.1 As part of the training events staff were asked to complete their own circle of intimacy. Participation in this exercise not only informed the support staff about the types of data collection techniques the researcher had employed with the research participants but enabled them to draw direct comparisons between their own social networks and those of the learning disabled people with whom they work. At the end of the training sessions staff were invited to submit their anonymous circle of intimacy diagrams to the researcher for further scrutiny. They were also informed that by doing so they would be consenting to having their data utilised for research purposes and possibly published in an academic journal. 24 of the 42 staff members were happy to have their information used in this way and left their circles of intimacy with the researcher.

5.2 Analysis of the 24 staffs' circles of intimacy diagrams revealed that they had larger, more diverse and more durable social networks than the learning disabled research participants. The staff had an average of 20 social contacts within their networks. The sources of their contacts were more varied and their relationships generally longer lasting.

5.3 The fact that the service users' social networks differed in some regards to from those of their paid support workers was no surprise to the researcher as similar variations in the make-up of learning disabled and non-learning disabled populations' social circles have been noted in previous research. What was more unexpected was the variation in the people that the service users and their support staff valued.

5.4 Both groups seemed to prize their families highly, as it was family members who appeared most frequently within the inner circles of the intimacy diagrams for both staff and learning disabled participants. Beyond this the similarity between staff and service users ceased, as the staff went on to people the middle and outer rings of their circle with 'friends' that they had accumulated over their life course from school, college, work and various shared activities. Only five staff members included a learning disabled client on their circle of intimacy and then only peripherally, whereas all 14 learning disabled participants placed at least one paid carer on their circle of intimacy, often near the middle of the chart. This provided an indication of just how central the participants considered their carers to be to their lives.

5.5 When asked what it was that they particularly valued about the staff the learning disabled research participants said that they could talk to them easily, they would listen to their problems, helped them with their college work, spoke clearly, gave them individual attention, made them laugh, took them out, and were enjoyable company. In short, the data suggested that staff were valued because they accepted clients for who they were, could offer practical assistance and information, and provided emotional support and advice. Interestingly, when given a choice of terms to describe the staff (carer, key worker, staff member, trainer, boss or friend) all 14 of the learning disabled research participants selected the term 'friend' to describe the individuals who worked with them. This was in sharp contrast to the staff who rarely included the service users on their charts nor considered them to be part of their friendship group.

5.6 The identification of such a clear disparity raised some important questions about how each group could perceive their interactions in such different ways. How could the learning disabled research participants perceive their staff as friends when the staff clearly did not classify them as such? Clearly it is important to understand what constitutes friendship, in particular the elements necessary to turn a social contact into a friendship. The sociological literature on friendship makes a useful distinction between friends (i.e. those engaged in a relationship) and friendship (i.e. the process of engagement) and identifies four key elements that are thought to set 'friendship interactions' apart from other human connections. These are: autonomy, equality, reciprocity and intimacy. The consensus amongst commentators on the subject is that friendships are relationships that are founded upon choice, shared values and interests, mutual reward, closeness, disclosures and trust.

5.7 By reviewing each of the 'friendship' elements, it is possible to reach an understanding of how the learning disabled service users and their support staff came to have contrasting views of one another that could co-exist. A description of each of the four elements and how they manifest themselves within the lives of both the service users and support staff follows.

Autonomy

6.1 Autonomy or the freedom to select and sustain one's friends is seen to be a central component of friendship. Unlike other social liaisons, friendship can be conceived as being unconstrained by role, responsibilities or employment contracts. This has led some, (Jamieson 1998:87, Little, 1998:11) to consider friendship to have the potential to be the most 'natural' or 'truest' form of relationship that one can experience.

6.2 It is questionable, however, just how 'natural' or 'true' friendship really is. Neither 'who' we select to be a friend nor 'how' we conduct our friendships is totally free. As Allan reminds us, our friendship choices are always tempered by what he terms the 'social and economic realities' of our lives (1996, p.94). It can be contended that the relationships options of people with learning disabilities are unusually constrained by these factors. The fact that many of those with learning disabilities are dependent upon services to meet their needs means they cannot dictate who they spend time with, or how that time is spent. Unlike others who come together through shared life roles or common interests, people with learning disabilities are more often than not grouped according to their 'condition'. The pool of individuals from which people with learning disabilities have to select their companions is typically limited to the service users and service providers with whom they have most day to day contact. Their lack of access to, or control over, their own finances also places significant restrictions upon the ability of people with learning disabilities to make and maintain relationships outside of the service setting. In reality most people with learning disabilities do not have access to the transport or technology required to sustain social contacts beyond those making contact with them. They are thus obliged to focus their attentions upon those who frequent the service circles in which they find themselves.

6.3 Given these parameters, it is unsurprising that paid carers feature prominently in the lives of people with learning disabilities as staff make up a substantial proportion of service users' social contacts. They are bound therefore to take on a particular significance to them. By comparison the staff's sources of social contacts are broader than the service users. The learning disabled people with whom they are paid to work represent only a small proportion of those 'available' to them. As a consequence the social position that people with learning disabilities occupy within the lives of their paid carers is a relatively reduced one, as staff have a much larger 'social network' from which to select their friendships. Indeed, based on the omission of those with learning disabilities from the staff's social circles, it would appear that paid carers afford people with learning disabilities little or no social significance compared to others in their networks.

6.4 The contrast in the size of the social pool people with learning disabilities and their paid carers have to draw upon perhaps goes some way to explaining the disparity in the relative importance each group assigns to one another. It does not account, however, for the different perspective they have about the autonomy of their relationships. On the whole, staff did not view their contact with service users to be voluntary or naturally occurring encounters (like the ones you might find between friends). They were more inclined to see them as 'contrived' liaisons which started, at least initially, as a direct result of them being paid to spend time with those with learning disabilities.

6.5 The learning disabled research participants' limited communications skills made it hard to ascertain exactly how autonomous they felt their relationships with their paid carers to be. Observations revealed, however, that within the confines of the day centre the service users were free to seek the company of whichever staff member or fellow service user they liked. They were also at liberty to switch their allegiances between them at will. Given the scope the service users had to fraternize with whomever they pleased at the day centre it is perhaps not unreasonable to assume that they perceived these relationships to be freely chosen liaisons that they had actively selected to pursue from the many available to them within the day centre environment. Indeed during the researcher discussions with the research participants only two individuals said they had ever felt coerced into spending time with people they did not like. (In

both instances the individuals alluded to being made to socialise with housemates that they felt no affinity for by their residential support staff.) The remaining 12 participants all reported being very satisfied with their current social set. This suggests that the majority were happy with the degree of autonomy they had to seek and select their own friends.

6.6 Without access to information about the nature and sources of other people's social contacts it is not difficult to see why the research participants might have reached the conclusion that thier relationships were autonomous as they were unaware of how much their social networks differed from others. Many were also oblivious to the fact that the staff were paid to be with them, as no money was ever directly exchanged between them and the staff. The lack of obvious recompense for services received undoubtedly led to some service users assuming that others were willing to 'meet their needs' out of a sense of altruism rather than as a result of professional duty or contractual obligation. It is no surprise therefore that so many of the learning disabled participants felt the staff members cared about them (rather than just for them) in a way that one friend might care about another.

Equality

7.1 Pahl believes equality is a 'necessary condition of friendship' (2000, p.21) as it is important that a balance (predominantly of power) exists between those who are engaged within such a relationship. Achieving this balance for people with learning disabilities has proved problematic for a number of reasons. Services have done much to try and redress some of the inequalities that exist between staff, service users and others, but their efforts have met with a varying degree of success. Measures such as doing away with staff uniforms and the abolition of staff titles have gone some way to reducing the disparity of status between staff and service users. As a consequence, services seem less hierarchical than they once were.

7.2 The learning disabled research participants certainly reported feeling as if they had closer, more personal contact with the staff in their present day centres and supported houses than they had ever had while residing in long-stay institutional care. Staff, on the other hand, while acknowledging that a new openness existed between themselves and the service users, were uncertain whether this actually equated to equality.

7.3 Attempting to equalise the power between individuals in any given relationships is a problematic process. As Oliver (1992) recognises, in order for power to be successfully transferred from one group to another it must not only be relinquished by the first group but taken up by the second. Staff suggest that this does not always happen, and that even if they are happy to surrender control, some service users are either unable or unwilling to assume responsibility for themselves. Although most staff appeared to support the notion of giving up their power, in principle, several staff members felt that relinquishing the authority that had been invested in them as carers would be tantamount to a dereliction of their caring duties. In short, they felt they needed to retain a degree of power if they were to adequately protect and provide for their vulnerable learning disabled charges. On this basis people with learning disabilities will never achieve an equal status to their staff.

7.4 Tensions were not only confined to the problem of trying to treat service users the same as staff, but also arose from staff attempts to treat each service user alike. Services have a moral imperative to deliver the same standard of care to all service users. The staff are thus encouraged to adopt an impartial stance, and discouraged from showing what might be construed as favouritism towards or accepting favours from any particular service user. While such an approach ensures that no individual is advantaged or disadvantaged relative to others, it can create a somewhat cold or aloof relationship between staff and service users as staff attempt to avoid 'over-engagement' by adopting what has come to be called 'professional distance'.

7.5 It would seem, therefore, that the attainment of equality paradoxically advances closer, more personal relationships between staff and service users, while at the same time promoting distant, more professional ones. This situation is confusing for both staff and service users, as neither group seems clear about where the social boundary between themselves and the others lies any longer. Given the confusion it is little wonder that many service users have misconstrued the friendliness the staff display towards them as friendship.

Reciprocity

8.1 The notion of reciprocity or 'exchange' is also very important within friendship interactions as compared to other social relationships. Friends are reported to trade information, support and sociability. But what constitutes a 'fair trade' is less widely documented. It would appear that the length and depth of a given relationship affects the rate and repayment period of any exchange but the terms and conditions of such exchanges never seem to be specified.

8.2 Rather than debate the relative value of what is being exchanged, or what constitutes an acceptable time between exchanges, it is probably more useful to think of reciprocity in terms of mutual reward. Some authors believe that friendships will be sustained only if they meet the mutual satisfaction of those involved in them (Jamieson,1998:85). The relationships people with learning disabilities have with their paid carers are often denied friendship status on the basis that they are not reciprocal. Those with learning disabilities are frequently portrayed as 'takers' who have little to give in 'return'. This notion can be contested however, as the learning disabled research participants were observed performing many 'acts of kindness' towards the staff as well as other service users during the course of the study. This suggests, therefore, that the process of exchange between staff and service users is not only restricted by the service users' inability or willingness to give, but is also curtailed by the staff's uncertainty about whether

or not to receive. Once again staff find themselves in the difficult position of not wishing to reject the service users advances as this may be taken as a personal rebuttal, but equally not wanting to accept them lest they should appear to be favouring one person over another.

8.3 Furthermore, it is easy to see how given that nothing the service users offer ever seems to be actively rejected by staff, they might have reached the conclusion that they are in fact in a reciprocal relationship with their paid carers, in which they engage in both give and take. In addition it is easy to see how service users might deduce that what they offer actually meets the needs of the staff (as they have not been informed otherwise) and that, as such, their relationship is a mutually satisfactory one – like that found between friends.

Intimacy

9.1 Intimacy or 'closeness' is normally a component of friendship. Just how intimacy is achieved between individuals is difficult to establish, although the literature emphasises the importance of proximity, disclosure, communication and trust in bringing individuals 'together'.

9.2 People with learning disabilities undoubtedly spend a lot of their time in close proximity to their paid carers. Indeed, staff have access to the most private spheres in the lives of people with learning disabilities as they are often required to assist individuals with very personal activities within their homes. While staff may view such tasks as a functional requirement of their jobs, it is plausible to believe that some learning disabled individuals attach more significance to these activities, not least because these may be the only occasions on which they receive any physical contact with others. The attention they are given from staff during times of practical assistance is bound, therefore, to feel intimate to them, although staff avoid describing it as such because physical intimacy between the carer and the cared for is considered taboo.

9.3 A further element within friendship is disclosure. Unlike many other social relationships friends are thought to disclose what Jamieson refers to as 'privileged knowledge' about themselves (1998:8). Little supports this when he says that friendliness becomes friendship only when confidences begin to be exchanged (1998:32). Paid carers are certainly in possession of 'privileged knowledge' about the service users, as even if the learning disabled individuals do not confide in the staff themselves, their case notes (to which staff have access) contain intimate details about their lives.

9.4 Communication is thought to be the mechanism by which greater intimacy between individuals is reached. Good communication is most frequently taken to mean verbal speech, indeed conversation has been credited by Little as the way in which we maintain 'the common consciousness that makes up relatedness itself' (1998, p.32). The learning disabled research participants certainly rated good communication as a major component in their relationship with staff. It was observed that many of those who had little or no verbal communication relied upon staff to 'translate' their thoughts and wishes. Indeed some individuals' lack of clear communication precluded them establishing relationships with anyone other than trained professionals or staff members as none of their learning disabled peers possessed the skills to make sense of their particular mode of communication. It is no wonder that staff and some professionals occupy a special position in these individuals' lives as they provide the medium through which they can express themselves.

9.5 Out of disclosure and communication comes trust. Pahl suggests that by exposing our vulnerabilities to others we place ourselves at risk of being betrayed. What bonds us to others is the belief that they will not reveal our confidences. Pahl consequently believes trust is 'at the heart of the ideal friendship' (2000, p.61). People with learning disabilities are unquestionably a vulnerable group of individuals who frequently find themselves with little choice but to trust others to meet their needs. The relationships the service users have with their paid carers are then, at least as far as those with the learning disability are concerned, based upon a high degree of trust.

9.6 Again, it is not difficult to see why, from the service users' perspective, they feel they are part of an intimate relationship in which they share their personal space, past secrets and present aspirations with staff.

The reaction of service providers to the study findings

10.1 It was evident from the discussions that the researcher had with staff during the training sessions that many felt unclear about how to frame their relationships with those with learning disabilities. Most felt they had a responsibility to facilitate the service users' friendships by teaching them social skills, arranging social events or sorting out misunderstandings that occurred between them but few appeared to have considered they might have a role in becoming friends with the service users themselves.

10.2 Indeed, a few staff members appeared awkward when informed that those with learning disabilities perceived their paid carers as friends. Some admitted that this revelation had forced them to reconsider how they felt about the relationships they shared with their own clients, as introducing the notion of 'friendship' complicated what they had previously considered to be a straightforward caring arrangement.

10.3 Interestingly, having been made aware of the service user's feelings towards them, some staff believed they had a duty to try and 'change' the service users' perceptions of their relationship to be more in line with their own. A few felt that not to try and do so was a deceit which would result in people with learning disabilities being denied the opportunity to experience the depth and breadth of relationships that others enjoy, as they would continue to engage in a form of pseudo-friendship with staff, which they felt fell short of being 'the real thing'. These individuals believed that by maintaining the status quo they might

hamper the learning disabled people with whom they worked from integrating more fully into society. They therefore advocated that their clients' social horizons be broadened beyond the cosseted day centre environment, that their awareness be raised about the nature and source of other people's friendships and they be informed about the payment staff received to work with them.

10.4 Other staff members were less sure about trying to alter the service users' perceptions of themselves. These individuals believed there was little harm in people with learning disabilities continuing to hold the views that they do about staff and that to expose their relationships as not being friendships was an unnecessarily cruelty, particularly when directed at those who have precious few friends anyway. They also felt that, although segregated, the day centre offered those with learning disabilities a unique forum in which they could conduct their relationships in the way they wished, free from the intervention of others, and that it ought to be preserved because of this.

Conclusion

11.1 It is evident, therefore, that there is still a great deal of confusion surrounding the way in which people with learning disabilities and their support staff relate to one another. As with many of the non-familial relationships discussed in this special edition the boundaries between these two groups are ill-defined. Indeed, neither group appears to have a clear frame of reference about how they should behave towards the other. Those with learning disabilities have few social experiences to guide them through their interactions with staff. It is perhaps not surprising therefore, that in the absence of any other comparisons they have come to conclude that their relationships with their staff look and feel like friendships. The staff, in turn, seem equally ill-advised about how to engage with the service users, as they have not received any directions about how to respond to their particular perceptions of them. The vague rules that services set-down about professionalism certainly do not provide any precise guidance about how they ought to conduct their day to day relationships with the learning disabled people with whom they work.

11.2 In the absence of any normative consensus about their interactions, each service user and support staff member is left to negotiate the parameters of their relationship. This has proved notoriously problematic for those with learning disabilities and their associates. Traditionally commentators have attributed the difficulties that people with intellectual impairments encounter when attempting to make or maintain friendships to factors associated either to their own 'lack of adjustment' or society's 'lack of acceptance' (Mills 1998). Writers such as Whittaker and Garbarino (1983) and Stainback and Stainback (1987) support the 'lack of adjustment' theory, proposing that it is people with learning disabilities limited skills, undesirable personal characteristics and 'general lethargy' that leads to their exclusion. In short, they hold the individual and their failings responsible for their paucity of relationships. Critics of this standpoint believe that by pathologizing the causes of a disabled person's exclusion, we fail to acknowledge society's role in their diminished social networks. Proponents of the 'lack of acceptance' theory place greater emphasis upon the barriers which society puts in the way of friendships. As such, they view the problems that people with learning disabilities face when attempting to establish a social circle to be a consequence of society's failure to adequately facilitate their community presence and participation. This is equally the case whether that be through lack of access or opportunity to use services and facilities or the negative attitudes they experience when attempting to do so.

11.3 Having considered these perspectives it becomes clear that neither of these explanations offer the total solution, as they seem to imply that the remedy to people with learning disabilities' relationship problems lies either in the action of the individual (i.e. the learning disabled person) or the actions of the collective (i.e. the staff). The study indicates that what is actually required is the successful 'inter-action' of the two. What inhibits these groups achieving this state of inter-action is neither the service users' intellectual impairment nor the restrictive attitudes of the staff, but the problems inherent in trying to reconcile the conflicts that exist within and between each of the elements thought necessary to achieve friendship.

11.4 As the study progressed it became evident that each of the four 'friendship' elements identified were indeed vital to the development of those with learning disabilities' meaningful social interactions, as together they combine to promote the individual and their relatedness to other people. Autonomy and equality, for example, could be said to champion the self, while reciprocity and intimacy address our interaction with others, both of which are essential to the development of valued relationships. That said, it also became apparent that far from working in harmony all of the elements were actually in dynamic tension with each other, as the pursuit of a single element over and above the others could upset the delicate balance that exists between them and result in an individual's relationships being compromised. The need to maintain a degree of equilibrium between each of the elements is what creates the biggest challenge for staff in particular as they are faced with having to juggle the needs of the individual for more autonomy and intimacy, and the demands of the collective for greater equality and reciprocity.

11.5 Preliminary discussions, following feedback of the initial findings, with a small group of paid carers suggest that they do not feel adequately equipped to manage these tensions, as they have not received any guidance or training about how to do so. This in turn results in them feeling confused and indecisive about their role with regards to their clients' relationships. Providing any recommendations about what sort of training is required by staff requires more in-depth study, but it does need to be addressed as not to do so may influence the quality of those with learning disabilities' existing relationships and jeopardize their chances of making and maintaining valued relationships with those in the broader community in the future.

References

ALLAN G. (1996) Kinship *and Friendship in Modern Britain.* Oxford University Press: Oxford.

ATKINSON D. (1987) How Easy is it to Form Relationships? *Social Work Today* 12-13.

BIRKETT EM. (1984) A Comprehensive Study of the Effects of the Makaton Vocabulary and a Language Stimulation Programme on the Communication Abilities of Mentally Handicapped Adults.

COHEN A.P. (1985) *The Symbolic Construction of Community*. London. Routledge.

COLLINS J. (1997) Integration or Sanctuary? *Community Care*. 29:23-29

COOPER P. (1998) A Population Based Cross-Sectional Study of Social Networks and Demography in Older Compared with Younger Adults with Learning Disabilities. *Journal of Learning Disabilities for Nursing, Health and Social Care,* 2 (4), 212-220.

DEPARTMENT OF HEALTH (2001) Valuing *People: A New Strategy for Learning Disability for the 21st Century*. HMSO, CM 5086.

DETHERIDGE T. and Detheridge M (2nd Edition) (2002) Literacy through Symbols: Improving access for Children and Adults. David Fulton Publishers Ltd. London.

EMMERSON E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press. Cambridge.

EVANS G. & Murcott A. (1990) Community Care: Relationships and Control. *Disability, Handicap and Society*. 5(2): 123-135.

GRAY B. and Ridden G. (1999) *Lifemaps of People with Learning Disabilities.* Jessica Kingsley Publications. London.

JAMIESON L. (1998) Intimacy*: Personal Relationships in Modern Society*. Polity Press: Cambridge.

LITTLE G. (1998) Friendship*: Being Ourselves with Others.* The Text Publishing Company, Melbourne: Australia.

MILLS L. (1998) Integration of Adults with Learning Disabilities into the Community: Support Persons Perspectives, Unpublished PhD thesis, University of Edinburgh.

NEWTON S., Olson D., Hoiner R. and William R. (1996) Social Skills and the Stability of Social Relationships between Individuals with Intellectual Disabilities and Older Community Members. *Research in Developmental Disabilities* 17 (1), 15-26.

OLIVER M. (1992). Changing the Social Relations of Research Production. *Disability, Handicap and Society*, 7.

PAHL R. (2000) *On Friendship*. Polity Press: Cambridge.

PAHL R. and Spencer L. (2004) Chapter 6: Capturing Personal Communities – from Phillipson, Allan and Morgan (*Eds*) (2004) *Social Networks and Social Exclusion: Sociological and Policy Perspectives.*

QURESHI H. and Alborz A. (1992) the Epidemiology of Challenging Behaviour. Mental Handicap Research. 5, 130-145

RALPH A. (1995) Social Interactions of People with Developmental Disabilities Living Independently in the Community. *Research in Developmental Disabilities* 16 (3), 149-163.

REDWORTH M. & Redworth F. (1997) Learning Disability and Citizenship: paradigms for inclusion. *Journal of Learning Disability Nursing, Health and Social Care*. 1(4): 181 – 185

RICHARDSON A. and Ritchie J. (1989) Developing *Friendships: Evaluating People with Learning Disabilities Ability to Make and Maintain Friends*. London: Policy Studies Institute.

SMULL M. and Burke Harrison S. (1992) Supporting *People with Severe Reputations in the Community*. Baltimore: National Association of State Directors of Developmental Disabilities Services Inc.

STAINBACK W. & Stainback S. (1987) Facilitating Friendships. *Education and Training in Mental Retardation*. March. 18-25.

WALES A., Gilhooly M., and Curzio J. (2001). *The Netboard: A tool for measuring support networks in research practice.* Poster Presentation, Glasgow Caledonian University.

WESOLOWSKI M. (1987) Differences in Size of Social Networks of Rehabilitation Clients versus those of Non-Clients. *Rehabilitation Counselling Bulletin*, 17:27.

WHITTAKER J.K. & Garbarino J. (1983) Social Support Networks: Informal Helping in Human Services. New York, Aldine Publishing Company